DOCUMENT RESUME

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ABSTRACT

The purpose of this directory is to facilitate networking and collaboration among those caring for or providing support services to children with chronic illness or disabling conditions. It is hoped that this directory will enable parents to identify other parents who share their interests and concerns, as well as assist professionals in locating parents whose skills and expertise can assist them in improving community support for children with special needs and their families. The directory, which includes a section for Canada, is organized by state and province under which parents are listed alphabetically. Information provided for each parent includes name, address, telephone numbers, child's or children's disability, group affiliation, health care facility where child receives majority of care, the parent's skills and interests, the parent's experiences in promoting a family-centered approach to health care, the parent's profession, and the year(s) during which the parent has participated in the association's Parent Network meetings. Indexes are provided for parents' names and for disabilities. (VW)

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Parent Resource Directory

for
Parents and Professionals
Caring for Children with
Chronic Illness or Disabilities

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1st Edition
February 1987

EC 201209

Association for the Care of Children's Health

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Parent Resource Directory

1st Edition
February 1987

Association for the Care of Children's Health
3615 Wisconsin Avenue, N.W., Washington, D.C. 20016
(202)244-1801 or (202) 244-8922

Introduction

The purpose of this directory is to facilitate networking and collaboration among those caring for or providing support services to children with chronic illness or disabling conditions. It is hoped that this directory will enable parents to identify other parents who share their interests and concerns, as well as assist professionals in locating parents whose skills and expertise can assist them in improving community support for children with special needs and their families.

This is the first edition of the Parent Resource Directory. An expanded and updated edition will be published in the summer of 1987. A Parent Resource Directory Information Form can be found on page 85 of this directory. Please share this form with parents who would like to be included in the future editions of the directory, or to make corrections or changes in listings in this edition. Completed forms should be returned to ACCH by June 15, 1987. In addition, please use the evaluation form on page 89 to give us feedback on ways to improve this directory and increase its usefulness.

We hope that this directory will be a valuable resource to those who are caring for children with special needs. We look forward to hearing from you and welcome your suggestions.

Organization of the Directory

The directory is organized by state and province, with parents listed alphabetically within each state or province. In addition, there is a general alphabetical index of parents, as well as an index listing parents by their child's disability at the end of the directory. The following information is presented in this directory:

Parent Name
Address
Phone (when two numbers are given the first one is the daytime phone)
Child's or children's disability
Group affiliation
Health care facility where child receives majority of care
The parent's skills and interests
The parent's experiences in promoting a family-centered approach to health care
Parent's profession
Year(s) that parent has participated in ACCH Parent Network meetings

When categories of information are not applicable or were not provided by the parent, they are omitted. An asterisk (*) before a group affiliation indicates that it is a Parent Training and Information Center, a federally funded program to provide information to parents on the special education laws.

ARIZONA

Barbara Hopkins
1005 E. Carver Road
Tempe, AZ 85284
602 838-9006

Child's disability: Prune Belly Syndrome; scoliosis
Group affiliations: Prune Belly Syndrome Parent Network
Arizona Consortium for Children with Chronic Illness - Director
Skills and interests: Parent-to-parent support and advocacy; parent/professional collaboration
Experience: Parent Representative, Arizona Consortium for Children with Chronic Illness; public speaking; leading training for health providers/teachers; promoting legislation; starting or maintaining support groups; working with state health departments
Profession: R.N.
Participation in ACCH Parent Network meetings (years): 1986

Susan Larkin
720 E. Brentrup
Tempe, AZ 85283
602 897-9745

Child's disability: Congenital heart defect
Group affiliation: Arizona Consortium for Children with Chronic Illness
Health care facility where child receives majority of care: Phoenix Children's Hospital - Phoenix, AZ
Skills and interests: Parent/professional collaboration
Experience: Chairperson, Parent Advisory Council, Phoenix Children's Hospital; public speaking; leading training for health providers/teachers; promoting legislation; working with state health departments
Profession: Executive Director, Arizona Consortium for Children with Chronic Illness

Susan Mann
2005 N. Central
Suite 100
Phoenix, AZ 85004
602 271-4012
602 969-8209

Child's disability: Multiple handicaps; medically fragile (deceased)
Group affiliation: *Pilot Parents - Program Coordinator
Skills and interests: Parent-to-parent support; bereavement issues; working with families of medically fragile and at-risk children
Experience: Public speaking; leading training for health providers/teachers; promoting legislation; starting or maintaining support groups; working with state health departments
Profession: Program Coordinator, *Pilot Parents

Betsy Trombino
2005 N. Central, #100
Phoenix, AZ 85004
602 271-4012
602 942-8626

Child's disability: Dwarfism; orthopedic complications
Group affiliation: *Pilot Parents - Program Director
Skills and interests: Parent-to-parent support; statewide issues for medically at-risk individuals; services for medically fragile
Experience: Member, Arizona Consortium for Children with Chronic Illness; Advisory Board Member, NICHCY (National Information Center for Handicapped Children and Youth); Member, Parent Advisory Council, Phoenix Children's Hospital; public speaking; leading training for health providers/teachers; promoting legislation; starting or maintaining support groups; working with state health departments
Profession: Program Director, *Pilot Parents
Participation in ACCH Parent Network meetings (years): 1984, 1986

ARKANSAS

Susan Gregory
Route 3 Box 350 G
Rogers, AR 72756
501 636-2410
501 631-6202

Child's disability: Seizures controlled by brain surgery
Skills and interests: Parent to parent support; working with families with children having brain surgery
Profession: Teacher

CALIFORNIA

Donna G. Albrecht
4603 Lincoln Drive
Concord, CA 94521
415 825-6861

Child's disability: Werdnig-Hoffmann disease
Group affiliations: Werdnig-Hoffmann Parent Support Group
Muscular Dystrophy Association
Families of Spinal Muscular Atrophy
Health care facility where child receives majority of care: Kaiser - San Francisco, CA
Skills and interests: Parent-to-parent support; sports programs for children with disabilities
Experience: Public speaking; leading training for health providers/teachers; starting or maintaining support groups
Profession: Freelance writer
Participation in ACCH Parent Network meetings (years): 1986

Jane Armfield
544 87th Street
Colma, CA 94015
415 992-7095

Child's disability: Ondine's curse
Health care facility where child receives majority of care: Children's Hospital - San Francisco, CA
Skills and interests: State funding for home care for medically fragile
Experience: Leading training for health providers/teachers
Participation in ACCH Parent Network meetings (years): 1986

Sherelyn Campbell
1015 Cedar Street
Santa Cruz, CA 95060
408 335-7404

Children's disabilities: Portal hypertension; hematological conditions
Atonic bladder/stoma
Group affiliation: Circle of Hope - Founder
Health care facilities where children receive majority of care:
Stanford University Medical Center - Stanford, CA; Children's Hospital at Stanford - Palo Alto, CA
Skills and interests: Parent-to-parent support; editor of monthly newsletter; bereavement issues
Experience: Member, Parent Advisory Board, Children's Hospital at Stanford; public speaking; leading training for health providers/teachers; starting or maintaining support groups; working with state health departments
Participation in ACCH Parent Network meetings (years): 1986

June Carrin
2378 Sutter Street
San Francisco, CA 94115
415 346-6998
415 728-7071

Children's disabilities: Nager's Syndrome
Severely deaf
Skills and interests: Support for families; adoption of children with handicaps; public awareness of children with special needs
Experience: Public speaking; leading training for health providers/teachers; promoting legislation; starting or maintaining support groups; working with state health departments
Profession: Clinical psychologist
Participation in ACCH Parent Network meetings (years): 1986

Joan Cassel
2741 Valley Street
San Francisco, CA 94123
415 346-6858
415 567-4014

Child's disability: Down Syndrome
Group affiliation: Support for Parents With Special Children - Education Director
Health care facility where child receives majority of care: Children's Hospital - San Francisco, CA
Skills and interests: Parent-to-parent support and discussion groups; information and resources for parents; networking with parents of children with similar needs
Experience: Public speaking; leading training for health providers/ teachers; starting or maintaining support groups; working with state health departments
Profession: Social worker; doctoral student in educational psychology

Kerry Dunn
972 Adams Street
Albany, CA 94706-2022
415 526-9351

Child's disability: Cystic fibrosis
Health care facility where child receives majority of care: Children's Hospital - Oakland, CA
Skills and interests: Insurance coverage for high risk groups; parent-to-parent support; parent involvement in policy development
Experience: Former Director, Kentucky Cystic Fibrosis Services; starting or maintaining support groups; working with state health departments
Participation in ACCH Parent Network meetings (years): 1986

Mary Fauvre
8833 Woodley Avenue
Sepulveda, CA 91343
213 825-8529
818 892-7915

Child's disability: Leukemia (ALL)
Health care facility where child receives majority of care: UCLA Hospital - Los Angeles, CA
Skills and interests: Support to parents of chronically ill children
Experience: Public speaking; leading training for health providers/teachers; starting or maintaining support groups; working with state health departments
Profession: Parent Liaison, Oncology Unit - UCLA Hospital
Participation in ACCH Parent Network meetings (years): 1985, 1986

Betty Pinkle
16000 West Road
Los Gatos, CA 95030
408 354-4188

Child's disability: Hemophilia (classical)
Group affiliation: Northern California Hemophilia Foundation - Membership Chairperson
Health care facility where child receives majority of care: Stanford Children's Hospital - Palo Alto, CA
Skills and interests: Parent-to-parent support; hospice care
Experience: Starting or maintaining support groups
Profession: R.N.; Volunteer, Hospice of the Valley

Sharon Gilbert
131 Miramonte
Fullerton, CA 92635
714 871-2864

Child's disability: Sturge-Weber Syndrome
Skills and interests: Training medical and educational professionals; teaching parenting classes; parent advocacy; parent/professional collaboration
Experience: Developed curriculum for nurses caring for children with handicaps; public speaking; leading training for health providers/teachers; promoting legislation; starting or maintaining support groups; working with state health departments
Profession: Consultant/Counselor; freelance lecturer on children's health care issues
Participation in ACCH Parent Network meetings (years): 1985, 1986

Sharman Davis Jamison
1033 North La Jolla
Los Angeles, CA 90046
213 663-3223
213 650-4827

Child's disability: Autism; profoundly deaf
Group affiliation: Lanterman Regional Center
Health care facility where child receives majority of care: Children's Hospital - Los Angeles, CA
Skills and interests: Sales and marketing of educational music programs for children aged 3 to 9
Experience: Member and past President, Board of Directors, Lanterman Regional Center; public speaking; promoting legislation
Profession: National Sales Director, Educational Music for Children

Monica Loose Jones
433 E. Pedregosa Street
Santa Barbara, CA 93103
805 569-2407

Child's disability: Werdnig-Hoffmann disease
Group affiliations: Families of Spinal Muscular Atrophy
SKIP
Leukodystrophy Group
Skills and interests: All aspects of pediatric home care; comfort care for the terminally ill
Experience: Member, state and national task forces on home care of medically fragile children; public speaking; leading training for health providers/teachers; promoting legislation; working with state health departments
Profession: Author, Home Care for the Chronically Ill or Disabled Child: A Manual & Sourcebook for Parents and Professionals; consultant on issues related to pediatric home care
Participation in ACCH Parent Network meetings (years): 1984, 1985.

Anna Belle Kaufman
1784 N. Crescent Heights Blvd.
Los Angeles, CA 90069
213 656-6193

Child's disability: Bronchopulmonary dysplasia; tracheotomy and gastrostomy now closed; immune deficiency
Group affiliation: Good Beginnings
Health care facility where child receives majority of care:
Cedars-Sinai Medical Center - Los Angeles, CA
Skills and interests: Parent support and networking; reducing trauma of repeated hospitalizations for families
Experience: Author of article for parents on coping with hospital system; leading training for health providers/teachers; starting or maintaining support groups

Miftah H. MacNeil
562 East 19th Street
Chico, CA 95928
916 891-5865
916 342-7107

Child's disability: Juvenile ceroid lipofucinosis; visual impairment; learning disability
Group affiliations: ARC - Butte County - Respite Program Coordinator
Pilot Parents
FOCUS - Co-facilitator
Health care facility where child receives majority of care: University of California at San Francisco - San Francisco, CA
Skills and interests: Parent support; self-esteem building for families; collaborative programs for parents and professionals; education for disability awareness; holistic perspectives in care and education
Experience: Vice President for Parent Programs of Community Advisory Committee, Butte County SELPA (Special Education Local Plan Area); Co-facilitator, FOCUS; Member and past Chair, Pilot Parent Committee, ARC; public speaking; promoting legislation; starting or maintaining support groups; working with state health departments
Profession: Respite Program Coordinator, ARC - Butte County

Ellen Parker
2437 D Street
La Verne, CA 91750
714 593-2827

Child's disability: Down Syndrome
Group affiliations: Project COPE
ARC
Skills and interests: Parent-to-parent support
Experience: Board Member, ARC; starting or maintaining support groups; working with state health departments
Participation in ACCH Parent Network meetings (years): 1986

Lynn Powell
2700 Azusa, #155
West Covina, CA 91792
818 965-6473

Child's disability: Kidney disease
Group affiliation: KIDS (Keys to Introducing Disabilities in Schools)
Health care facility where child receives majority of care: UCLA Hospital - Los Angeles, CA
Skills and interests: Conducting programs for children and teachers on disabilities; developing family support group
Experience: Public speaking; leading training for health providers/teachers; starting or maintaining support groups; working with state health departments
Participation in ACCH Parent Network meetings (years): 1986

Florene Poyadue
535 Race Street, Suite 220
San Jose, CA 95126
408 288-5010
408 251-1987

Child's disability: Down Syndrome
Group affiliation: Parents Helping Parents, Inc. - Executive Director
Skills and interests: Parent-to-parent support and education; parent/professional collaboration; statewide networks of parent groups across disabilities
Experience: Public speaking; leading training for health providers/teachers; promoting legislation; starting or maintaining support groups; working with state health departments
Profession: R.N.; Executive Director, Parents Helping Parents
Participation in ACCH Parent Network meetings (years): 1985, 1986

Karen Rath
2126 Lamer Street
Burbank, CA 91504
818 842-4575

Child's disability: Trisomy 4P; asthma; seizures; closed brain injury affecting motor abilities
Group affiliations: Baseline
P.O.N.D. (Parents of Near Drowners)
Skills and interests: Networking with families of near-drowners
Profession: Certified occupational therapist assistant
Participation in ACCH Parent Network meetings (years): 1986

Dale and Roswitha Robinson
1962 Asilomar Drive
Oakland, CA 94611
415 428-3382
415 339-2769

Children's disabilities: Cnarcot-Marie-Tooth atrophy
Mental retardation
Group affiliation: ARC
Health care facility where children receive majority of care:
Children's Hospital - Oakland, CA
Skills and interests: Independent living skills; transition to independent living; networking with parents
Experience: Working with state health departments
Participation in ACCH Parent Network meetings (years): 1986

Joan Stoddard
22 Pintail
Irvine, CA 92714
714 962-6332
714 551-0729

Child's disability: Cerebral palsy; visual impairment; learning disability
Group affiliations: *TASK (Team of Advocates for Special Kids) - Project Coordinator
Community Advisory Council, Irvine Unified School District
Legislative Action Network
National Foundation of Wheelchair Tennis
National Handicap Ski Association
Health care facilities where child receives majority of care:
University of California - Irvine, CA; Stanford University - San Jose, CA
Skills and interests: Parent training in PL 94-142; advocacy for families with children with special needs; parent support
Experience: Public speaking; leading training for health providers/teachers; promoting legislation; starting or maintaining support groups; working with state health departments
Profession: Project Coordinator, *TASK (Team of Advocates for Special Kids)

Joanne Travers
872 Purdue Street
Upland, CA 91786
714 982-2804

Child's disability: Cerebral palsy (grandchild)
Group affiliation: COPE (Community Outreach for Parent Education)
Skills and interests: Parent-to-parent support; parent/professional collaboration
Experience: Development and marketing of parent education project; public speaking; leading training for health providers/teachers
Profession: Program Developer, Project COPE
Participation in ACCH Parent Network meetings (years): 1983, 1984

Dorothy Williams
834 22nd Street
Santa Monica, CA 90403
213 855-4431
213 453-2274

Child's disability: Premature birth
Group affiliations: Good Beginnings
Parent Care
Health care facility where child receives majority of care:
Cedars-Sinai Medical Center - Los Angeles, CA
Experience: Coordinates all parent support services to families with infants in the NICU; liaison with parents, social work, and medical staff; public speaking; leading training for health providers/teachers; starting or maintaining support groups
Profession: Parent Counselor, Cedars-Sinai Medical Center
Participation in ACCH Parent Network meetings (years): 1983

Linda Wurzbach
111 Cantas Place
San Ramon, CA 94583
415 786-0901
415 829-1852

Child's disability: Spina bifida and hydrocephalus; learning disability
Group affiliations: Spina Bifida Association of San Francisco Bay Area
COPE - Outreach to Parents
Health care facility where child receives majority of care: Kaiser Hospital - Walnut Creek, CA
Skills and interests: Special education issues for parents and professionals; collaboration among medical/educational professionals and parents
Experience: State consultant for special education and medical issues; public speaking; leading training for health providers/teachers; starting or maintaining support groups;
Profession: Parent specialist, State Department of Special Education
Participation in ACCH Parent Network meetings: 1986

COLORADO

Paula Wray
20190 Amy Court
Colorado Springs, CO 80908
303 574-2345
303 495-0270

Child's disability: Cleft lip and palate
Group affiliations: National Cleft Palate Association
Colorado Cleft Palate Association
*P.E.A.K. (Parents Education and Assistance for Kids
Health care facility where child receives majority of care: Children's Hospital, University of Colorado Health Sciences Center - Denver, CO
Skills and interests: Parent training and information; insurance issues for cleft lip and palate
Experience: Member, Board of Directors, National Cleft Palate Asssociation; Past President, Colorado Cleft Palate Association; public speaking; leading training for health providers/teachers; promoting legislation; starting or maintaining support groups
Profession: Occupational therapist; Information specialist, *P.E.A.K.

CONNECTICUT

Ruth Norton
33 Old Bethel Road
Newtown, CT 06470
203 426-5453

Child's disability: Agenesis of the corpus callosum
Group affiliation: Learning Together
Newtown Citizens with Alternate Needs
Parent to Parent Network
Health care facilities where child receives majority of care: Yale New Haven Hospital - New Haven, CT; Newington Children's Hospital - Hartford, CT
Skills and interests: Parent-to-parent support and education; recreation activities and programs for children with special needs
Experience: Member, Advisory Board, Newington Children's Hospital Pediatric Rehabilitation and Training Center; Member, Parent/Professional Advisory Board, Newtown Special Education; Coordinator, summer program for children with special needs age 3 to 9; aide in PROBE program; public speaking; starting or maintaining support groups
Participation in ACCH Parent Network meetings (years): 1986

DELAWARE

Darlene Bonavita
640 Buckson Drive
Dover, DE 19901
302 734-3535
302 734-5153

Child's disability: Cerebral palsy
Group affiliation: Parents for the Support of Handicapped Children
Health care facility where child receives majority of care: Alfred I. Dupont Hospital - Wilmington, DE
Skills and interests: Parent-to-parent support; editor of monthly newsletter for support group
Experience: Public speaking; promoting legislation; starting or maintaining support groups; working with state health departments
Profession: Secretary

Emily Tarpley
9 Vassar Drive
Newark, DE 19711
302 738-6934

Child's disability: Turner's Syndrome
Group affiliation: Human Growth Foundation, D.C. Chapter - Board Member and Treasurer
Health care facility where child receives majority of care: Johns Hopkins University Hospital - Baltimore, MD
Skills and interests: Creating network between genetic groups; prepared education program for teachers, parents and professionals about abnormal growth patterns and short stature; psychosocial aspects of short stature;
Experience: Assisted in development of Iowa Health Care Guidelines for Families; public speaking; leading training for health providers/teachers; promoting legislation; starting or maintaining support groups
Profession: Teacher

DISTRICT OF COLUMBIA

Minna Newman Nathanson
2025 Eye Street Suite 1011
Washington, DC 20006
202 659-5136
202 244-5803

Child's disability: Leukemia (deceased)
Group affiliation: Candlelighters Childhood Cancer Foundation - Director of Publications
Skills and interests: Medical and psychosocial information for parents and professionals; editor; early childhood development and education
Experience: Public speaking; leading training for health providers/teachers; promoting legislation; starting or maintaining support groups
Profession: Director of Publications, Candlelighters Foundation
Participation in ACCH Parent Network meetings (years): 1983, 1984, 1985, 1986

Marsha Parker
3328 Martin Luther King Avenue S.E.
Washington, DC 20032
202 727-3866
202 563-5971

Child's disability: Multiple handicaps
Group affiliation: *Parents Reaching Out Service, Inc.
Handicapped Infant Intervention Project
Epilepsy Foundation
Health care facility where child receives majority of care: Children's Hospital National Medical Center - Washington, DC
Skills and interests: Parent-to-parent support; parent training and education
Experience: Public speaking; leading training for health providers/teachers; starting or maintaining support groups; working with state health departments
Profession: Director, Parent Resource Center, *Parents Reaching Out Service

FLORIDA

Joan Gebo
3115 Coral Hills Drive #D-1
Coral Springs, FL 33065
305 755-7917

Children's disabilities: Bronchopulmonary dysplasia; near-SIDS; gastroesophageal reflux
Bronchopulmonary dysplasia; epilepsy; T & B cell antibody deficiency
Group affiliation: SKIP of Florida - Director
Skills and interests: Parent networking and support
Experience: Starting or maintaining support groups
Profession: R.N., critical care

GEORGIA

Sue Anne Mitchell
2333 Parc Chateau Drive
Lithonia, GA 30058
404 482-6021

Child's disability: Moyamoya disease; achalasia
Health care facility where child receives majority of care: Children's Medical Services - Altanta, GA
Skills and interests: Legislative issues for families of children with special needs
Profession: R.N.; freelance artist

Carla Putnam
1851 Ram Runway
College Park, GA 30337
404 761-2745
404 941-3591

Child's disability: Learning disability
Group affiliation: *Parents Educating Parents - Director
Skills and interests: Technical assistance to parent programs; parent support and training
Experience: Leading training for health providers/teachers; promoting legislation; starting or maintaining support groups
Profession: Director, *Parents Educating Parents
Participation in ACCH Parent Network meetings (years): 1986

IDAHO

Lorena Freund
3309 E. Pinehill Drive
Coeur D'Alene, ID 83814
208 667-6409
208 667-8082

Child's disability: I-cell disease (deceased)
Group affiliation: PROP (Parents Reaching to Other Parents)
Health care facility where child received majority of care: Sacred Heart Hospital - Spokane, WA
Skills and interests: Parent-to-parent support
Experience: Public speaking; leading training for health providers/teachers; starting or maintaining support groups
Participation in ACCH Parent Network meetings (years): 1986

ILLINOIS

Faye Manaster Eldar
8331 Kimball Avenue
Skokie, IL 60076
312 677-3796

Child's disability: Deaf-blind; cerebral palsy
Group affiliation: Keshet: Jewish Families of Children with Special Needs - Co-President
Health care facility where child receives majority of care: Children's Memorial Hospital - Chicago, IL
Skills and interests: Parent outreach, training, information and referral; parent-to-parent support; preparing children for hospitalization; sensory impairments
Experience: Public speaking; starting or maintaining support groups; working with state health departments
Participation in ACCH Parent Network meetings (years): 1986

Chuck Frame
5843 N. West Circle
Chicago, IL 60631
312 631-0038

Child's disability: C-5 quadriplegia
Health care facility where child receives majority of care: Children's Memorial - Chicago, IL
Skills and interests: Home care for medically fragile
Experience: Public speaking; leading training for health providers/teachers; promoting legislation; starting or maintaining support groups; working with state health departments
Profession: Printing
Participation in ACCH Parent Network meetings (years): 1984

James Green
1730 Hinman Road, #4A
Evanston, IL 60201
312 864-9533

Child's disability: Osteoarthritis; pernicious anemia
Skills and interests: Film production; films and media materials about children with handicaps
Experience: Developed media campaign for NICHCY; Member,Advisory Board, Easter Seals; public speaking; leading training for health providers/teachers
Profession: Director Public Service Projects, Grey Chicago
Participation in ACCH Parent Network meetings (years): 1985, 1986

Audrey Lewis
1386 Glencoe Avenue
Highland Park, IL 60035
312 432-0594

Child's disability: Werdnig-Hoffmann disease
Group affiliation: Families of Spinal Muscular Atrophy - President
Health care facilities where child receives majority of care Shriners Hospital - Chicago, IL; Weiss Memorial - Chicago, IL; Children's Memorial - Chicago, IL
Skills and interests: Increasing public awareness; parent to parent support
Experience: Working on videotape of exercises for physically handicapped and able-bodied children
Participation in ACCH Parent Network meetings (years): 1985

Jennifer Paczynski
3133 N. George Street
Franklin Park, IL 60131
312 671-0088

Child's disability: Cancer (deceased)
Group affiliations: Chicagoland Candlelighters
Concerned Parents
Health care facility where child received majority of care: Children's Memorial - Chicago, IL
Skills and interests: Parent-to-parent support; early intervention
Experience: Member of Parent Board, Lutheran General Hospital; public speaking
Profession: R.N. at pediatric orthopedic hospital
Participation in ACCH Parent Network meetings (years): 1983

Audrey A. Simek
200 N. Riverwoods Road
Lake Forest, IL 60045
312 234-2412

Children's disabilities: Cystic fibrosis
Cystic fibrosis
Cystic fibrosis
Group affiliation: Simek Memorial Counseling Center - Founder and Executive Director
Skills and interests: Work with families of children with chronic illness; special interest in bereavement; psychosocial needs of families
Experience: Public speaking; leading training for health providers/teachers; starting or maintaining support groups
Profession: Psychotherapist
Participation in ACCH Parent Network meetings (years): 1986

INDIANA

Bobbie Fussichen
502 Mt. Dora Lane
Indianapolis, IN 46229
317 897-5166

Child's disability: Cerebral palsy
Group affiliations: Cerebral Palsy Support Group - Founder and Vice President
Parent Advisory Board - Methodist Hospital
Health care facility where child receives majority of care: Methodist Children's Hospital - Indianapolis, IN
Skills and interests: Advocacy for families of children with special needs; editor of newsletter
Experience: Member, Parent Advisory Board, Methodist Children's Hospital; public speaking; leading training for health providers/teachers; promoting legislation; starting or maintaining support groups; working with state health departments
Profession: R.N., psychiatric nurse clinician, Psychiatry Department, Methodist Hospital

Linda Hankins
1511 Maria Lane
Plainfield, IN 46168
317 839-6201

Child's disability: Down Syndrome
Group affiliation: Indiana Task Force on Early Childhood Special Education - Parent Coordinator
Health care facility where child receives majority of care: James Whitcomb Riley Hospital for Children - Indianapolis, IN
Skills and interests: Working to mandate special education for 0-5 year olds; establish parent training center
Experience: Parent Coordinator, Indiana Task Force on Early Childhood Special Education; public speaking; leading training for health providers/teachers; promoting legislation; starting or maintaining support groups; working with state health departments
Participation in ACCH Parent Network meetings (years): 1986

Joyce Jones
5005 Dickson Road
Indianapolis, IN 40226
317 542-0582

Child's disability: Spina bifida
Group affiliation: Spina Bifida Association of Central Indiana - President
Health care facility where child receives majority of care: James Whitcomb Riley Hospital for Children - Indianapolis, IN
Skills and interests: Parent-to-parent support; newsletter editor
Experience: Public speaking; promoting legislation

Ruth Kimberley
128 E. Sycamore
Vincennes, IN 47591
812 882-0375

Child's disability: Hunter's Syndrome
Group affiliation: Knox County Advocates for Special Kids - Founder
Health care facility where child receives majority of care: James Whitcomb Riley Hospital for Children - Indianapolis, IN
Skills and interests: Parent/professional collaboration; educating pediatricians
Experience: Public speaking; promoting legislation; starting or maintaining support groups; working with state health departments

Donna Lueking
Route 2 Box 117
Sullivan, IN 47882
812 382-4421

Child's disability: Juvenile diabetes
Group affiliation: Juvenile Diabetes Support Group - President
Health care facilities where child receives majority of care: Mary Sherman Hospital - Sullivan, IN; Methodist Children's Hospital - Indianapolis, IN
Skills and interests: Parent-to-parent support; legislative reform for health care; collaboration between state agencies and parents
Experience: President, Mary Sherman Hospital Foundation Board; Juvenile Diabetes Representative, Indiana National Voluntary Health Agencies Board; promoting legislation; working with state health departments
Participation in ACCH Parent Network meetings (years): 1986

Debra and James Morris
1141 E. Fairview Avenue
South Bend, IN 46614
219 232-3034
219 288-1079

Child's disability: Physical, visual and mental handicaps
Group affiliation: Parents Helping Parents - Founders
Health care facility where child receives majority of care: St. Joseph's Medical Center - South Bend, IN
Skills and interests: Long term medical financial planning; identification of services for families of children with special needs; legislation for children with handicaps; computer adaptations for special needs
Experience: Promoting legislation; starting or maintaining support groups; working with state health departments

Donna Olsen
2107 East 65th
Indianapolis, IN 46220
317 257-8683

Children's disabilities: Cystic fibrosis
Cystic fibrosis
Group affiliation: Parent Advisory Board - Methodist Children's Hospital - Chairperson
Health care facility where children receive majority of care: Methodist Children's Hospital - Indianapolis, IN
Skills and interests: Parent/professional collaboration; increasing awareness of needs of children with chronic conditions in hospital, school, and community
Experience: Chairperson, Parent Advisory Board, Methodist Hospital; public speaking; leading training for health providers/teachers; starting or maintaining support groups; working with state health departments
Participation in ACCH Parent Network meetings (years): 1984, 1985, 1986

Beverly Preske
2835 W. Booneville-New Harmony Road
Evansville, IN 47712
812 963-9010

Child's disability: Cerebral palsy
Group affiliations: Concerned Parent of the Retarded and Handicapped - President
Parents and Professionals Advocating for the Handicapped - President
TOUCH (To Our Understanding of Children with Handicaps) - Vice President
Health care facility where child receives majority of care: Deaconess Hospital - Evansville, IN
Skills and interests: Developed training program for parents; parent-to-parent support
Experience: Public speaking; leading training for health providers/teachers; promoting legislation; starting or maintaining support groups; working with state health departments
Profession: United Cerebral Palsy of Indiana

Connie Rahe
RR #1 Box 394
Muncie, IN 47302
317 358-4813

Child's disability: Cystic fibrosis
Group affiliation: Cystic Fibrosis Parent Support Group
Health care facility where child receives majority of care: Methodist Children's Hospital - Indianapolis, IN
Skills and interests: Parent-to-parent support
Experience: Public speaking; leading training for health providers/teachers; promoting legislation; starting or maintaining support groups; working with state health departments
Profession: Special education resource teacher

Pat Rieger
2110 E. 65th Street
Indianapolis, IN
317 257-6598

Child's disability: Duchenne's Muscular Dystrophy
Group affiliation: Muscular Dystrophy Support Group - Founder
Health care facility where child receives majority of care: Methodist Children's Hospital - Indianapolis, IN
Skills and interests: Parent-to-parent support
Experience: Member, Parent Advisory Board, Methodist Children's Hospital; public speaking; leading training for health providers/teachers; starting or maintaining support groups
Participation in ACCH Parent Network meetings (years): 1985

Connie L. Shella
7957 Dartmouth Road
Indianapolis, IN 46260
317 846-4206
317 253-2769

Child's disability: Diabetes; epilepsy
Group affiliation: American Diabetes Association
Health care facility where child receives majority of care: Methodist Children's Hospital - Indianapolis, IN
Skills and interests: Diabetes education; updating diabetes education for families; parent/professional collaboration; prenatal classes for diabetics
Experience: Member, Parent Advisory Board, Methodist Children's Hospital; Executive Board Member, American Diabetes Association; leading training for health providers/teachers; starting or maintaining support groups; working with state health departments
Profession: R.N.; Diabetes educator
Participation in ACCH Parent Network meetings (years): 1985, 1986

Carol Whetsel
442 E. State Street
Pendleton, IN
317 778-4192

Child's disability: Cystic fibrosis
Group affiliation: Cystic Fibrosis Parent Support Group
Skills and interests: Parent-to-parent support; organized family support conference
Experience: Public speaking; leading training for health providers/teachers; promoting legislation; starting or maintaining support groups
Participation in ACCH Parent Network meetings (years): 1985

IOWA

Julie Beckett
2420 D Avenue NE
Cedar Rapids, IA 52402
319 353-6173
319 362-0978

Child's disability: Post encephalitis; ventilator assisted
Group affiliation: SKIP of Iowa - Director
Health care facility where child receives majority of care: St. Luke's Methodist Hospital - Cedar Rapids, IA
Skills and interests: Funding for home care for medically fragile
Experience: Assisted in development of Iowa Health Care Guidelines for Families; Member, Governor's Planning Council on Developmental Disabilities; participates on Maternal and Child Health Advisory Council; Associate Director for Consumer Affairs, National Maternal and Child Health Resource Center, University of Iowa Law School; Parent Consultant, Parent-Educator Partnership Project; Vice Chairperson, Task Force on Technology Dependent Children, Department of Health and Human Services; public speaking; leading training for health providers/ teachers; promoting legislation; starting or maintaining support groups; working with state health, education and social service departments
Participation in ACCH Parent Networking meetings (years): 1985, 1986

Carla Lawson
33 N. 12th Street
P.O. Box 1151
Fort Dodge, IA 50501
515 576-5870

Children's disabilities: Werdnig-Hoffmann disease
Werdnig-Hoffmann disease (deceased)
Group affiliations: Iowa Exceptional Parent Center - Director
Health care facility where child receives majority of care: University Hospital - Iowa City, IA
Skills and interests: Parent education and training about PL 94-142; develops workshops for health care professionals; consults and develops resources for parent center at University Hospital
Experience: Public speaking; leading training for health providers/teachers; promoting legislation; starting or maintaining support groups; working with state health departments
Profession: Director, Iowa Exceptional Parent Center
Participation in ACCH Parent Network meetings (years): 1983, 1984, 1986

Jule Reynolds
1922 E 12th
Des Moines, IA 50316
515 263-9247

Child's disability: Cerebral palsy; seizures
Group affiliations: Special Care Parents - Chairperson
*Iowa Pilot Parents
Health care facilities where child receives majority of care: Iowa Methodist Medical Center - Des Moines, IA; Blank Children's Hospital - Des Moines, IA
Skills and interests: Technical assistance facilitator for department of education; parent consultant for education department
Experience: Parent Consultant, Department of Education; public speaking; leading training for health providers/teachers; starting or maintaining support groups; working with state health departments

KANSAS

Kathy Johnson
4445 N.W. 52nd Terrace
Topeka, KS 66618
913 267-4270
913 288-2114

Child's disability: Cerebral palsy
Group affiliation: *Families Together - Resource Coordinator
Health care facility where child receives majority of care: Kansas University Medical Center - Kansas City, KS
Skills and interest: Editor of newsletter; family enrichment weekends; coordinates Count Me In Puppets for parent training center
Experience: Member, Citizens Advisory Council on Preschool Handicapped; public speaking; leading training for health providers/teachers; promoting legislation; starting or maintaining support groups; working with state health departments
Profession: Resource Coordinator, *Families Together
Participation in ACCH Parent Network meetings (years): 1986

KENTUCKY

Lavonna King
5974 Rich Pond Road
Bowling Green, KY 42101
502 781-6111
502 843-6191

Child's disability: Cerebral palsy; multiple handicaps
Cerebral palsy; multiple handicaps
Group affiliation: Kentucky Commission for Handicapped Children - Chairperson
Health care facility where children receive majority of care: Jewish Hospital, Louisville, KY
Skills and interests: Education needs of children with special needs; parent-to-parent support
Experience: Chairperson, Kentucky Commission for Handicapped Children; Past Chairperson, United Cerebral Palsy Association, South Central Kentucky; public speaking; promoting legislation
Profession: Bank operations officer

Carmen Yates
1113 Chinoe Road
Lexington, KY 40502
606 269-1349

Child's disability: Cystic fibrosis
Group affiliations: Kentucky Cystic Fibrosis Services, Inc. - President
RISE (Resource Information and Support Exchange)
Health care facility where child receives majority of care: University of Kentucky Medical Center - Lexington, KY
Skills and interests: Parent-to-parent support; access to information
Experience: Member, Health Information Council; public speaking; starting or maintaining support groups; working with state health departments

LOUISIANA

Kathy and Dave Duff
P.O. Box 2716
Lafayette, LA 70502-2716
318 237-6948

Child's disability: Cerebral palsy
Group affiliation: Parents of Special Children - Secretary and President
Health care facility where child receives majority of care: Children's Hospital - New Orleans, LA
Skills and interests: Parent-to-parent support
Experience: Starting or maintaining support groups; working with state health departments
Participation in ACCH Parent Network meetings (years): 1984

MAINE

Marie Lowell
RFD #1 Box 1020
Buckfield, ME 04220
207 336-2657
207 336-2411

Child's disability: Down Syndrome
Group affiliation: The Child Health Center - Coordinator of Child Development Program
Health care facility where child receives majority of care: The Child Health Center - Norway, ME
Skills and interests: Identification and education of preschool children with special needs; outreach to parents and professionals; encouraging early referrals and intervention by professionals
Experience: Member, Governor's Advisory Board for the Bureau of Children with Special Needs; Chairperson, Local Coordinating Committee for Preschool Project; Chairperson, Local School Board; working with State Division of Maternal and Child Health; public speaking; leading training for health providers/teachers
Profession: Coordinator of Child Development Program, The Child Health Center

Sherry S. Pierce
Fairview Drive
P.O. Box 273
Fryeburg, ME 04037
207 935-2092
207 935-3616

Child's disability: Hypsarrhythmia; mixed seizure disorder
Health care facility where child receives majority of care: Massachusetts General Hospital - Boston, MA
Skills and interests: Respite care; parent/professional collaboration; parent advocacy
Experience: Member, Governor's Advisory Council for the Bureau of Children with Special Needs; public speaking; promoting legislation; working with state health departments
Profession: Sales manager for forest products company
Participation in ACCH Parent Network meetings (years): 1986

Jan Waite-Austin
36 High Street
Bath, ME 04530
207 389-1683

Child's disability: Cerebral palsy
Group affiliations: *SPIN (Special Needs Parent Information Network) - Parent Information Specialist
Project Search - Chair, Local Coordinating Committee
Health care facility where child receives majority of care: Boston Children's Hospital - Boston, MA
Skills and interests: Parent training in PL 94-142; help initiate parent support groups; help locate resources for families of children with special needs; family support issues
Experience: Chair, Local Coordinating Committee, Project Search; Former Parent Representative, Interdepartmental Committee for the Care of Preschool Handicapped Children; public speaking; leading training for health providers/teachers; starting or maintaining support groups; working with state health departments
Profession: Parent Information Specialist, *SPIN
Participation in ACCH Parent Network meetings (years): 1986

MARYLAND

Sandy Reckeweg
3957 Wintergreen Place
Waldorf, MD 20601
301 843-3937

Child's disability: Central hypoventilation syndrome; collapsible airway syndrome
Group affiliations: SKIP - Parent liaison
National Association for Home Care
Parents of Chronically Ill Children - Co-founder
Health care facility where child receives majority of care: Children's National Medical Center - Washington, DC
Skills and interests: Parent support and advocacy; writing directory of resources, services and helpful hints for families of technology assisted/medically fragile children
Experience: Parent Consultant, National Association for Home Care; public speaking; leading training for health providers/teachers; starting or maintaining support groups; working with state health departments
Profession: Mortgage loan officer
Participation in ACCH Parent Network meetings (years): 1986

Amita Sarin
7915 Declaration Lane
Potomac, MD 20854
301 299-5606

Child's disability: Cerebral palsy; blind; mental retardation
Group affiliation: Vision Parents Support Group
Health care facility where child receives majority of care: Children's Hospital National Medical Center - Washington, DC
Skills and interests: Training health professionals about the needs of families; ethical issues in treatment
Experience: Member, Ethics Forum, Children's Hospital National Medical Center; public speaking; leading training for health providers/teachers

Claudia Segal
1657 Yale Place
Rockville MD 20850
301 762-4858

Child's disability: Cerebral palsy; seizures
Health care facility where child receives majority of care: Children's Hospital National Medical Center - Washington, DC
Skills and interests: Parent-to-parent support; networking at the state and national level
Experience: Member, Committee for Special Needs, Jewish Community Center; leading training for health providers/teachers; starting and maintaining support groups; working with state health departments
Participation in ACCH Parent Network meetings (years): 1986

Karen Shannon
216 Newport Drive
Severna Park, MD 21146
301 647-0164

Child's disability: Respiratory; hearing impairment
Group affiliation: SKIP - Founder and National Executive Director
Skills and interests: Developing educational materials for families and professionals caring for children dependent on technology; public awareness
Experience: Member, Maryland work group to develop guidelines for PL 99-457; awarded Congressional fellowship to work on Capitol Hill; public speaking; leading training for health providers/teachers; promoting legislation; starting or maintaining support groups; working with state health and education departments
Participation in ACCH Parent Network meetings (years): 1984, 1985, 1986

MASSACHUSETTS

Betsy Anderson
9 Davis Avenue
Brookline, MA 02146
617 482-2915
617 566-5998

Child's disability: Spina bifida
Group Affiliations: *Federation for Children with Special Needs
Massachusetts Spina Bifida Association
Skills and interests: Parent/professional collaboration; family-centered programs; parent training in PL 94-142; health care financing
Experience: Parent Advisory Committee, Boston Children's Hospital; Chair, Consumer Concerns Committee, New England Regional Genetics Group; Congressional Committee on Health Care Financing for Technology Dependent Children; public speaking; leading training for health providers/teachers; promoting legislation; starting or maintaining support groups; working with state health departments
Profession: Director of Health Issues, *Federation for Children with Special Needs; Director, CAPP Project (Collaboration Among Parents and Health Professionals)
Participation in ACCH Parent Network meetings (years): 1984, 1985, 1986

Priscilla Bradway
18 Chandler Circle
Andover, MA 01810
617 475-0902

Child's disability: Cleft lip and palate; hemifacial microsomia
Skills and interest: Parent support group leader; sibling support and workshops for teachers
Experience: Member, Parent Advisory Committee, Boston Children's Hospital; public speaking; leading training for health providers/teachers; starting or maintaining support groups
Participation in ACCH Parent Network meetings(years): 1985, 1986

Betty Burton
52 Edgell Street
Gardner, MA 01440
617 632-7783

Child's disability: Toxoplasmosis
Group affiliation: Toxoplasmosis Foundation - Founder
Health care facilities where child receives majority of care: University of Massachusetts Medical Center - Worcester, MA; Massachusetts Eye and Ear Infirmary - Boston, MA; Massachusetts General Hospital - Boston, MA
Skills and interests: Parent education; parent-to-parent support group organizer; early intervention
Experience: Public speaking; leading training for health providers/teachers; promoting legislation; starting or maintaining support groups; working with state health departments
Participation in ACCH Parent Network meetings: 1985

Mr. and Mrs. Charles Fiske
70 Sewall Avenue
Brookline, MA 02146
617 566-3430

Child's disability: Organ transplant
Group affiliations: The Family Inn - Founder
New England Organ Bank
Skills and interests: Promoting legislation; developing housing for families of hospitalized children
Experience: Starting The Family Inn - a house for families to stay in while their children await organ transplants; public speaking; leading training for health providers/teachers; starting or maintaining support groups; working with state health departments

Brooke Heraty
24 Chenery Terrace
Belmont, MA 02178
617 484-1762

Child's disability: Cerebral palsy
Group affiliation: Mothers Support Group
Health care facility where child receives majority of care: Children's Hospital - Boston, MA
Skills and interests: Parent-to-parent support; education issues
Experience: Promoting legislation; starting or maintaining support groups
Participation in ACCH Parent Network meetings: 1985

Patricia Krug
21 Vine Rock Street
Dedham, MA 02026
617 326-4775
617 326-5537

Child's disability: Neurofibromatosis
Group affiliation: National Neurofibromatosis Foundation - Director of Operations, MA Chapter
Health care facilities where child receives majority of care: Massachusetts General Hospital - Boston, MA; Boston Children's Hospital - Boston, MA
Skills and interests: Fund raising; increasing public awareness; support for families
Experience: Officer with Massachusetts Chapter of the National Neurofibromatosis Foundation for 7 years

Janet Miller
737 Bay Road Box 7
Hamilton, MA 01936
617 468-1006

Child's disability: Spina bifida and hydrocephalus
Group affiliation: Massachusetts Spina Bifida Association
Health care facility where child receives majority of care: New England Medical Center - Boston, MA
Skills and interests: Parent-to-parent support; coping and medical management; bracing, equipment resources, and accessible environments; church involvement
Experience: Advisory Board, Adaptive Environments Center; hospital internships; brace shop work; public speaking; leading training for health providers/teachers
Profession: Rehabilitation counselor
Participation in ACCH Parent Network meetings (years): 1985

Barbara Popper
31 Wilshire Park
Needham, MA 02192
617 444-3877

Child's disability: Paralysis of facial nerve
Group affiliation: Children in Hospitals - President
Skills and interests: Support for families in hospitals; psychosocial policies and programs in hospitals; parent/professional collaboration at state level
Experience: Member, Parent Advisory Board, Boston Children's Hospital; developed Consumer Directory of Hospital Policies in Massachusetts; public speaking; leading training for health providers/teachers; promoting legislation; starting or maintaining support groups; working with state health departments
Participation in ACCH Parent Network meetings (years): 1985, 1986

Margie Saphier
56 Bellows Hill Road
Carlisle, MA 01741
617 369-4467

Child's disability: Hearing impairment
Group affiliations: Children in Hospitals - Newsletter Editor
*Federation for Children with Special Needs
Skills and interests: Parent advocacy in health care settings
Experience: Member, Parent Advisory Board, Massachusetts General Hospital; public speaking; leading training for health providers/teachers; promoting legislation; starting or maintaining support groups; working with state health departments
Participation in ACCH Parent Network meetings (years): 1985

Janet Vohs
312 Stuart Street
Boston, MA 02116
617 482-2915
617 731-3410

Child's disability: Cerebral palsy
Group affiliation: *Federation for Children with Special Needs
Skills and interests: Parent training in care management and coordination of care; community supports for families with special needs; early education policy
Experience: Public speaking; leading training for health providers/teachers; promoting legislation; starting or maintaining support groups; working with state health departments
Profession: *Federation for Children with Special Needs; Assistant Director, CAPP Project (Collaboration Among Parents and Health Professionals)
Participation in ACCH Parent Network meetings (years): 1986

Nora Wells
9 Washington Street
Lexington, MA 02173
617 482-2915
617 862-2680

Child's disability: Cerebral palsy
Group affiliation: *Federation for Children with Special Needs
Health care facilities where child receives majority of care: Children's Hospital - Boston, MA; New England Medical Center - Boston, MA
Skills and interests: Promoting legislation on health care financing; parent/professional collaboration
Experience: Member, Parent Advisory Board, Boston Children's Hospital; Parent Advisory Board, New England Medical Center; public speaking; leading training for health providers/teachers; promoting legislation; starting or maintaining support groups; working with state health departments
Profession: Consultant, CAPP Project (Collaboration Among Parents and Health Professionals), *Federation for Children with Special Needs
Participation in ACCH Parent Network meetings (years): 1983, 1985, 1986

Joanne Buzzo Wilhelm
7 Helena Drive
Tyngsboro, MA 01879
617 649-7573

Child's disability: Degenerative neuromuscular disease (deceased)
Skills and interests: Education needs of 0-3 year olds; parent education and support; collaboration with medical and education professionals
Participation in ACCH Parent Network meetings (years): 1985, 1986

MICHIGAN

Mark Chesler
University of Michigan
Dept of Sociology
4028 LSA Building
Ann Arbor, MI 48104
313 747-3654
313 764-7487

Child's disability: Cancer
Group affiliation: Candlelighters Childhood Cancer Foundation - National President
Skills and interests: Parent/professional collaboration; development of national parent support groups
Experience: Public speaking; leading training for health providers/teachers; starting or maintaining support groups; working with state health departments
Profession: Professor of Sociology, University of Michigan
Participation in ACCH Parent Network meetings (years): 1983, 1984

Yvonne De Paepe
1105 S. Clinton Avenue
St. Johns, MI 48879
517 224-4383

Child's disability: Severe physical and mental impairment
Group affiliation: Clinton County Support Group for Parents with Handicapped Children - Founder
Health care facility where child receives majority of care: University of Michigan Hospital - Ann Arbor, MI
Skills and interests: Parent-to-parent support; state legislative issues
Experience: Promoting legislation; starting or maintaining support groups; working with state health departments
Profession: Driver for school district

Connie Fischer
44 John Ball Park Drive NW
Grand Rapids, MI 49504
616 458-8744

Child's disability: Trisomy 18
Group affiliations: Mercy Respite Care Center - 1st President
SKIP of Michigan
Foundation for Hospice and Home Care
Families and Friends of Disabled Persons
Health care facility where child receives majority of care:
Butterworth Hospital - Grand Rapids, MI
Skills and interests: Home care and insurance for medically fragile children; education and awareness of family needs and support in long term chronic, catastrophic illness in children; family support and advocacy for families with developmentally disabled children; promoting support of continuum of respite services for families with developmentally disabled children; insurance issues
Experience: Public speaking; promoting legislation; starting or maintaining support groups; working with state health departments
Profession: R.N.

Carolyn Fowler
3675 Shoshone SW
Grandville, MI 49418
616 457-5380
616 534-3568

Children's disabilities: Multiple congenital anomalies
Down Syndrome; blind; hearing impairment
Group affiliations: ARC
Michigan Protection and Advocacy Service
Health care facility where children receive majority of care:
Butterworth Hospital - Grand Rapids, MI
Skills and interests: Advocacy and assistance for families; home care; job advocacy for developmentally disabled
Experience: Serves on advisory boards for Developmental Disabilities Services, Community Mental Health, and *CAUSE (Citizens Alliance to Uphold Special Education); public speaking; promoting legislation; starting or maintaining support groups; working with state health departments
Profession: Case manager, State Protection and Advocacy Services
Participation in ACCH Parent Network meetings (years): 1983, 1984

Patricia and John Hanley
1224 Berten Street
Lansing, MI 48910
517 372-8094

Children's disabilities: Cerebral palsy; visual impairment
Cerebral palsy; visual impairment
Group affiliations: United Cerebral Palsy of Lansing - Treasurer
SEPAC (Special Education Parent Advisory Committee)
The Parent Support Group
Skills and interests: Parent-to-parent support; advocacy for families with children with special needs; legislation issues
Experience: Treasurer, United Cerebral Palsy of Lansing; Chairperson, PTA, Center Program School, Lansing School District; public speaking; promoting legislation; starting or maintaining support groups; working with state health departments

Beverly McConnell
2990 Syckelmoone
Trenton, MI 48183
313 557-5070
313 675-7593

Child's disability: Cerebral palsy; apnea; epilepsy
Group affiliation: *United Cerebral Palsy Association of Metropolitan Detroit - Training Coordinator
Northwestern Guidance Respite Care Program
Community Mental Health Developmental Disabilities Advisory Committee
Wayne County Regional Interagency Coordinating Committee
Health care facility where child receives majority of care: Children's Hospital of Michigan - Detroit, MI
Skills and interests: Promoting advocacy skills for parents of children with special needs; training parents on PL 94-142
Experience: Founder, Parent Advisory Council, Northwestern Guidance Respite Care Program; Past President, Early Intervention Parent Advisory Council; Member, ARC; public speaking; leading training for health providers/teachers; promoting legislation; starting or maintaining support groups
Profession: Training Coordinator, Parents Training Parents Project, *United Cerebral Palsy Association of Metropolitan Detroit

Deborah Russell
9785 North 30th Street
Richland, MI 47083
616 629-4985

Child's disability: Trachealstenosis
Group affiliations: SKIP of Michigan
*CAUSE (Citizens Alliance to Uphold Special Education)
Health care facility where child receives majority of care: Children's Hospital of Michigan - Detroit, MI
Skills and interests: Insurance and home care needs for medically fragile; support for families
Experience: Consumer representative to Upjohn; works with Developmental Disabilities Council; planning family conference at Michigan State University; public speaking; promoting legislation; starting or maintaining support groups; working with state health departments

Paula Vander Meulen
513 Carrier N.E.
Grand Rapids, MI 49505
616 456-3818
616 456-1897

Child's disability: Severe congenital physical anomalies
Group affiliations: ARC of Kent County
Parents and Friends of Disabled
Health care facility where child receives majority of care: University of Michigan - Ann Arbor, MI
Skills and interest: Comfort and psychotherapy with families and groups; crisis counseling for health professionals
Experience: ACCH editorial board; parent resource to staff in pediatric neurology and orthopedics, University of Michigan Hospital; consultant to planning division for state CCS; public speaking; leading training for health providers/teachers; starting or maintaining support groups; working with state health departments
Profession: Social worker
Participation in ACCH Parent Network meetings (years): 1983, 1984

Connie Wells
65646 Middle Colon Road
Burr Oak, MI 49030
616 489-5385

Children's disabilities: Epilepsy; learning disability
Central apnea; ventricular tachycardia; seizures; hypothermia
Apnea; epilepsy
Group affiliations: SKIP of Michigan
Apnea Support Group
Health care facility where children receive majority of care:
University of Michigan - Ann Arbor, MI
Skills and interests: Insurance coverage for home health care; educational advocacy
Experience: Public speaking; leading training for health providers/teachers; promoting legislation; starting or maintaining support groups; working with state health departments

MINNESOTA

LuAnn Jelinek
140 W. Richmond Street South
St. Paul, MN 55075
612 455-3903

Children's disabilities: Cerebral palsy; hyperactive
Profound mental retardation; seizures; cleft lip and palate; crying disorder; severe stomach disorder
Skills and interests: Respite care; conducts training sessions for respite care and for foster care parents; spiritual needs of handicapped children
Experience: Public speaking; leading training for health providers/teachers; promoting legislation; starting or maintaining support groups; working with state health departments
Profession: Social worker
Participation in ACCH Parent Network meetings (years): 1986

Jean Mandeville
2 West Street
Albans Road
Hopkins, MN 55343
612 936-0946

Child's disability: Osteogenesis imperfecta
Group affiliations: Osteogenesis Imperfecta Association
*PACER (Parent Advocate Coalition for Education -Rights)
Minnesota Human Genetics League
Skills and interests: Resources for parents; parent/professional collaboration; research in genetics
Experience: President, Minnesota Osteogenesis Imperfecta Association; President, Minnesota Human Genetics League; developed written and audio visual materials on osteogenesis imperfecta; promoting legislation; worked to increase research funds for osteogenesis imperfecta
Participation in ACCH Parent Network meetings (years): 1986

Virginia Richardson
4044 Oakland Avenue South
Minneapolis, MN 55407
612 827-2966
612 822-3464

Child's disability: Mental retardation; epilepsy
Group affiliation: *PACER (Parent Advocate Coalition for Education -Rights) - Parent Training Coordinator
Skills and interests: Parent training in PL 94-142
Profession: Parent Training Coordinator, *PACER

Linda Rother
782 Sunset Drive
Eagan, MN 55121
612 454-3537

Children's disabilities: Hearing impairment; learning disability
Seizures; developmental delays; mental retardation; migraines
Ataxia; seizures; hyperflexia; hypotonia; infantile apnea; developmental delays
Skills and Interests: Parent/professional collaboration; early education for handicapped children; developing computer software for learning disabled
Experience: Public speaking; leading training for health providers/teachers; promoting legislation; starting or maintaining support groups; working with state health departments
Profession: R.N.
Participation in ACCH Parent Network meetings (years): 1986

MISSISSIPPI

Kathy Odle
Route 1, Box 119
New Site, MS 38859
601 728-5121

Children's disabilities: Neuro Axon I Dystropny
Neuro Axon I Dystrophy
Group affiliation: North Mississippi Coalition for Handicapped Residents - President
Children's Medical Program Parent Advisory Committee - Chairperson
Health care facility where children receives majority of care: Blake Clinic, Children's Medical Program - Mississippi State Board of Health
Skills and interests: Parent-to-parent support; respite and home care services; access to information for parents; parent/professional collaboration
Experience: Member, Children's Medical Program Advisory Board; Newsletter Editor, North Mississippi Coalition for Handicapped Residents; public speaking; leading training for health providers/teachers; promoting legislation; starting or maintaining support groups; working with state health departments
Profession: School attendance officer
Participation in ACCH Parent Network meetings (years): 1986

MISSOURI

Judy Shaw
716 East High Street
Jefferson City, MO 65101
314 635-2511

Child's disability: Leukemia
Group affiliation: Candlelighters Childhood Cancer Foundation
Health care facility where child receives majority of care: Cardinal Glennon Memorial Hospital for Children - St. Louis, MO
Skills and interests: Parent-to-parent support; public education
Experience: Public speaking; leading training for health providers/teachers; starting or maintaining support groups; working with state health departments
Participation in ACCH Parent Network meetings (years): 1983

NEBRASKA

B.J. and Chris Reed
113 South 50th Avenue
Omaha, NE 68132
402 554-2625
402 556-5509

Child's disability: Short bowel syndrome
Health care facilities where child receives majority of care: Children's Memorial Hospital - Omaha, NE; Swanson Center for Nutrition - Omaha, NE
Skills and interests: Parent-to-parent support; insurance issues for families with children with chronic illness
Experience: Public speaking; promoting legislation; starting or maintianing support groups; working with state health departments
Profession: Professors of Public Administration

Brenda Sutton
7616 Bauman Avenue
Omaha, NE 68122
402 346-5220
402 571-4862

Child's disability: Down Syndrome
Group affiliation: Pilot Parents - Program Coordinator
Health care facility where child receives majority of care: University Medical Center - Omaha, NE
Skills and interests: Providing information and support to families at time of diagnosis; work with hospitals to refer families to Pilot Parents
Experience: Public speaking; leading training for health providers/teachers; starting or maintaining support groups; working with state health departments
Profession: Coordinator, Pilot Parents

NEVADA

Joanne C. Brownlie
2221 McCoiq Avenue
Las Vegas, NV 89119
702 736-8555
702 736-8302

Children's disabilities: Down Syndrome
Bilateral cleft lip and palate; learning disabilities

Group affiliations: CHANCE (Coalition for Handicapped Children's Education) - Coordinator, Parent Advisory Liaison Project
South Nevada Down Syndrome Organization
Special Education Parent Advisory Committee

Skills and interests: Information and assistance for families of children and youth with special needs from birth through 21 years; linking parents with other parents and community services; liaison between families and the school district or community agencies

Experience: Past President, South Nevada Down Syndrome Organization; Representative, Special Education Parent Advisory Committee; public speaking; leading training for health providers/teachers; promoting legislation; starting or maintaining support groups; working with state health departments

Profession: Coordinator, Parent Advisory Liaison Project, CHANCE

Deborah Davis
3015 Heights Drive
Reno, NV 89503
702 747-5392
702 747-5110

Children's disabilities: Congenital fibertype disproportion
Congenital fibertype disproportion
Group affiliations: CHANCE (Coalition for Handicapped Children's Education) - Project Coordinator, Parents Helping Parents Project
N-STEP (Nevada Specially Trained Effective Parents) - Information Coordinator
Health care facility where children receive majority of care: Special Children's Clinic - Reno, NV
Skills and interests: Support for families; training on PL 94-142; helping families learn coping skills; parent/professional collaboration
Experience: Parent Member, State Special Education Advisory Committee; Member, Standards Revision Task Force; Member, Board of Directors, Very Special Arts; Advisory Board Member, HAPPY (Home Activity Program for Parents and Youth); Member, Advisory Committee, Member, Parent Auxiliary, PACEER; Member, Board of Directors, Special Children's Clinic; public speaking; leading training for health providers/teachers; promoting legislation; starting or maintaining support groups; working with state health departments
Profession: Project Coordinator, Parents Helping Parents Project, CHANCE; Information Coordinator, N-STEP

NEW HAMPSHIRE

Judy Lindquist
11 East Dunstable Road
Nashua, NH 03060
603 888-7706

Child's disability: Premature birth
Group affiliations: Parents of Premies - Board Member
Parent Care
Health care facility where child receives majority of care: Memorial Hospital - Nashua, NH
Skills and interests: Parent and family support
Experience: Starting or maintaining support groups

Martha-Jean and Robert Madison
RFD #1 Box 169A
Pittsfield, NH 03263
603 942-5540

Children's disabilities: Mental retardation; physical handicaps
Severe cerebral agenesis; severe medical needs
Cerebral palsy; mental retardation
Developmental delay; attention deficit
Emotional disturbance
Learning disability; hearing impairment
Splenectomy
Group affiliation: *New Hampshire Parent Information Center (P.I.C.)
Health care facilities where children receive majority of care: Concord Clinic - Concord, NH; Mary Hitchcock Hospital - Hanover, NH
Skills and interests: Coordinating services for children with special needs; workshops for families; public relations
Experience: Public speaking; leading training for health providers/teachers; starting or maintaining support groups; working with state health departments
Profession: Respite/Specialized Homes Coordinator (Robert)

R. Carol Wallenstein
8 Kent Street
Concord, NH 03301
603 225-9683

Child's disability: Congenital rubella syndrome; deaf-blind
Group affiliations: International Association for Education of Deaf-Blind (I.A.E.D.B.)
The Canadian Deaf-Blind and Rubella Association
Health care facility where child receives majority of care: Concord Hospital - Concord, NH
Experience: Past Board Member, State Parent Information Center, New Hampshire Educational Services for Visually Impaired; North-American Regional Coordinator, I.A.E.D.B.; Past State Parent Representative, New England Regional Center for Deaf-Blind Children; Past State Parent Representative Region I Center for Services to Deaf-Blind Children; promoting legislation; working with state health departments

NEW JERSEY

Rona Birnbaum
7 Washington Park
Maplewood, NJ 07040
201 789-4368
201 763-1474

Child's disability: Spina bifida
Group affiliation: Spina Bifida Association of Metropolitan New Jersey
Health care facility where child receives majority of care: Children's Specialized Hospital - Mountainside, NJ
Skills and interests: Fund raising for orthopedic appliances; support to new parents
Experience: Starting or maintaining support groups
Profession: Sales representative for Merrill Lynch
Participation in ACCH Parent Network meetings (years): 1986

Diana Cuthbertson
630 Fairmont Avenue
Westfield, NJ 07090
201 654-4333

Child's disability: Visual impairment; learning disabilities; recovered from cancer
Group affiliations: *Federation for Children with Special Needs, CAPP Project (Collaboration Among Parents and Health Professionals) - Consultant
National Association for Parents of the Visually Impaired
Adaptive Environments Center
Health care facility where child receives majority of care: Children's Hospital of Philadelphia - Philadelphia, PA
Skills and interests: Developing evaluation materials for parent training programs; bringing the parent perspective to the health care plan; parent networking; parent/professional collaboration
Experience: Member, American Foundation for the Blind, Early Years Advisory Committee; Board Member, National Association for Parents of the Visually Impaired; Past Chairperson, Massachusetts Developmental Disabilities Council Task Force on Family Support; public speaking; leading training for health providers/teachers; promoting legislation; starting or maintaining support groups; working with state health departments
Profession: MPH; R.N.

Annette Tocco
14 Ohio Terrace
Medford, NJ 08055
609 953-0656

Children's disabilities; Microcephaly
Microcephaly
Skills and interests: Parent advocacy; parents as case managers

NEW MEXICO

Polly Arango
P.O. Box 338
Algodones, NM 87001
505 867-3159

Child's disability: Cerebral palsy
Group affiliation: Parents Reaching Out (PRO) - President
Health care facility where child receives majority of care: El Pueblo Health Clinic - Bernalillo, NM
Skills and interests: Parent advocacy and organizing; medical, educational, and social issues for children with special needs in the foster care system; writing and editing
Experience: Developed legislation that led to Medically Fragile Children's Program; Former Member, Medically Fragile Children's Program Advisory Board; Former Board Member, Carrie Tingley Hospital; Board Member, El Pueblo Health Clinic; writing and editing speeches, fact sheets, brochures, articles; public speaking; leading and planning training for health providers/teachers; promoting legislation; starting or maintaining support groups; working with state health departments
Profession: Freelance writer; Consultant to non-profit agencies providing outreach to handicapped children and families

Loretta A. Armenta
6405 Concordia NE
Albuquerque, NM 87109
505 881-1111
505 821-4763

Child's disability: Sturge-Weber Syndrome
Group affiliation: Parents Reaching Out (PRO)
Skills and interests: State support for home care for medically fragile children; medical services for minorities and indigent; adolescent issues
Experience: Member, Medically Fragile Children's Program Advisory Board; public speaking; leading training for health providers/teachers; promoting legislation; starting or maintaining support groups; working with state health departments
Profession: Insurance agent
Participation in ACCH Parent Network meetings (years): 1985, 1986

Patti Bearpaw
7008 Aztec N.E.
Albuquerque, NM 87110
505 293-5800
505 884-4198

Child's disability: Diaphragmatic hernia; ventilator dependent
Group affiliations: SKIP of New Mexico
Rainbow House
Health care facility where child receives majority of care: University of New Mexico Hospital - Albuquerque, NM
Skills and interests: State and national legislative issues; family support
Experience: Public speaking; leading training for health providers/teachers; promoting legislation; starting or maintaining support groups; working with state health departments
Profession: Real estate
Participation in ACCH Parent Network meetings (years): 1984

Patti Ikard
1820 Muscatel
Carlsbad, NM 88220
505 885-2363

Child's disability: Down Syndrome
Group affiliations: Special Kids Project - Director
Parents Reaching Out (PRO)
ARC
Skills and interests: Training parents and professionals on PL 94-142; lobbyist for parent groups to mandate special education for 0-3
Experience: Co-chair and Parent Advisor, New Mexico Legislative Education Study Committee; Parent Advisor, Handicapped Children's Early Education Plan; Parent Representative, Governor's Committee for Chronically Impaired; Chairperson, Committee on Uninsurables
Profession: Director, Special Kids Project; Field Site Coordinator, Family Support Project for PRO

Dale Lautenschlager
566 Todd Loop
Los Alamos, NM 87544
505 672-9726

Child's disability: Multiple impairments
Group affiliation: Parents Reaching Out (PRO) - Board Member
Skills and interests: Parent-to-parent support
Experience: Public speaking; leading training for health providers/teachers; promoting legislation; starting or maintaining support groups; working with state health departments
Participation in ACCH Parent Network meetings (years): 1985

Marion Schroeder
7810 Charger Trail, N.E.
Albuquerque, NM 87109
505 821-5435

Child's disability: Cystic fibrosis
Group affiliation: Cystic Fibrosis Foundation
Health care facility where child receives majority of care: University of New Mexico Hospital - Albuquerque, NM
Skills and interests: Parent-to-parent support; insurance for high risk individuals; transitional care for children with chronic illness
Experience: Public speaking; leading training for health providers/teachers; promoting legislation; starting or maintaining support groups; working with state health departments
Participation in ACCH Parent Network meetings (years): 1986

Cathie Thomas
7418 Palm Lane, S.W.
Albuquerque, NM 87105
505 841-6143
505 831-2247

Children's disabilities: Bronchopulmonary dysplasia; Down Syndrome
Bronchopulmonary dysplasia; hydrocephalus
Group affiliation: Parents Reaching Out (PRO) - Vice President
Health care facilities where children receive majority of care:
University of New Mexico Hospital - Albuquerque, NM; Presbyterian Hospital - Albuquerque, NM
Skills and interests: Support for families with medically fragile children
Experience: Member, Medically Fragile Children's Program Task Force; public speaking; leading training for health providers/teachers; promoting legislation; starting or maintaining support groups; working with state health departments
Profession: Social worker, Human Service Division
Participation in ACCH Parent Network meetings (years): 1986

Tammy West
7303 Montgomery, N.E. H-190
Albuquerque, NM 87109
505 881-8835

Child's disability: Medically fragile; profoundly handicapped (deceased)
Group affiliation: Parents Reaching Out (PRO)
Skills and interests: Support for families with medically fragile children; promoting legislation to support families and children
Experience: Chairperson, Medically Fragile Children's Program Advisory Board; Member, New Mexico Developmental Disabilities Planning Council; public speaking; leading training for health providers/teachers; promoting legislation; working with state health departments
Profession: Parent Advisor, Developmental Disabilities Division, University of New Mexico
Participation in ACCH Parent Network meetings (years): 1984, 1985

NEW YORK

Dawne Flammger
14 Leawood Drive
Tonawanda, NY 14150
716 633-5333
716 695-8007

Child's disability: Diaphragmatic hernia; mild cerebral palsy
Group affiliation: AGAPE Parent Fellowship - Director
Health care facility where child receives majority of care: Children's Hospital - Buffalo, NY
Skills and interests: Parent-to-parent support; training for medical students; developing respite care facility; systems for telephone support
Experience: Public speaking; leading training for health providers/teachers; promoting legislation; starting or maintaining support groups
Profession: Travel agency manager

Margaret Mikol
500 East 83rd Street
Suite 113
New York, NY 10028
212 734-0728
212 628-5994

Child's disability: Ventilator dependent (deceased)
Group affiliation: SKIP of New York - Executive Director
Health care facility where child received majority of care: New York Hospital - New York, NY
Skills and interests: Family advocacy
Experience: Public speaking; leading training for health providers/teachers; promoting legislation; starting or maintaining support groups; working with state health departments
Profession: Executive Director, SKIP of New York

NORTH CAROLINA

Frank Graziadei
6915 Dulverton Drive
Charlotte, NC 28226
704 595-6123
704 365-1219

Children's disabilities: Duchenne's Muscular Dystrophy
Learning disability
Group affiliation: Exceptional Children's Advocacy Council - Chairperson
Health care facility where children receive majority of care:
Charlotte Rehabilitation Center - Charlotte, NC
Skills and interests: Educating professionals who work with families with exceptional children; parent/professional collaboration
Experience: Past President, Muscular Dystrophy Association, South Piedmont Chapter; public speaking; leading training for health providers/teachers; promoting legislation; starting or maintaining support groups; working with state health departments
Profession: Financial planner for IBM

Joanne Mackey
213 Haverhill Drive
Fayetteville, NC 28304
919 486-1605
919 868-1408

Child's disability: Spina bifida and hydrocephalus
Group affiliations: Parents Helping Parents - Coordinator
Spina Bifida Association of South Central NC - Past President
Skills and Interests: Parent-to-parent support; legislative action for children with chronic illness; developing "Whole Parents Catalog" for parents of children with special needs
Experience: Grant and Legislative Liaison, Spina Bifida Association of South Central North Carolina; public speaking; leading training for health providers/teachers; promoting legislation; starting or maintaining support groups; working with state health departments
Profession: R.N.
Participation in ACCH Parent Network meetings (years): 1986

Janet Sonnenberg
162 Virginia Road
Box 58
Montreat, NC 28757
704 669-5599

Child's disability: Burns
Health care facility where child receives majority of care: Shriners Burn Institute - Boston, MA
Skills and interests: Family-centered care policies/programs in hospitals; writing and public awareness about children with burns
Experience: Member, Family-Centered Care Committee, Shriners Burn Institute; public speaking
Profession: R.N.
Participation in ACCH Parent Network meetings (years): 1985, 1986

Beth Stewart
Route 1, Box 412
Haw River, NC 27258
919 684-3401
919 578-5038

Child's disability: Cancer (rhabdomyosarcoma)
Group affiliations: Parents and Professionals Together - Program Director, Duke University Medical Center
Parents Reach Out - Board Member
Skills and interests: Parent support; pediatric hospice care; writing handbook for parents of children with cancer; statewide parent networking; sibling support and education for siblings
Experience: Public speaking; starting or maintaining support groups
Profession: R.N.; Parent Consultant/Nurse Clinician, Pediatric Hematology/Oncology, Duke University Medical Center
Participation in ACCH Parent Network meetings (years): 1986

OHIO

Pat Hackett-Waters
621 Mehring Way, Apt. 801
Cincinnati, OH 45202
513 541-3663
513 241-4952

Child's disability: Spinal Muscular Atrophy
Group affiliation: Families of Spinal Muscular Atrophy - Education Consultant
Skills and interests: Educational consultant; parent-to-parent support; training parents as care managers
Experience: Public speaking; leading training for health providers/teachers; promoting legislation; starting or maintaining support groups;
Profession: M.Ed.; Teacher
Participation in ACCH Parent Network meetings (years): 1983, 1984, 1985, 1986

George and Bobbie Sich
4815 Carlow Circle
Middletown, OH 45042
513 423-0243

Child's disability: Spina bifida
Group affiliations: Spina Bifida Association of Cincinnati
Ohio Spina Bifida Coalition - Secretary
Middletown City Schools, Parent Advisory Council for Special Education
Spina Bifida Association of America
Health care facility where child receives majority of care: University of Cincinnati, Center for Developmental Disabilities - Cincinnati, OH
Skills and interests: Educational issues for children with special needs; parent support and advocacy
Experience: Vice President, Bylaws Chairperson and Strategic Planning Chairperson, Spina Bifida Association of America; public speaking; leading training for health providers/teachers; promoting legislation; starting or maintaining support groups; working with state health departments
Profession: Speech pathologist (Bobbie); Engineer (George)

Ann Toomey
2169 Glenbury Street
Lakewood, OH 44107
216 221-0926

Children's disabilities: Spina bifida
Spina bifida
Group affiliation: Greater Cleveland Spina Bifida Association
Health care facility where children receive majority of care:
Cleveland Clinic - Cleveland, OH
Skills and interests: Parent-to-parent support; outreach to families; parent/professional collaboration
Experience: Public speaking; leading training for health providers/teachers; promoting legislation; starting or maintaining support groups; working with state health departments

OREGON

Marie Deatherage-Newson
2432 S.E. Madison
Portland, OR 97214
503 234-2644

Child's disability: Spina bifida and hydrocephalus
Group affiliation: Columbia River Spina Bifida Association
Skills and interests: Newsletter editor; parent-to-parent support
Experience: Public speaking; leading training for health providers/teachers; starting or maintaining support groups; working with state health departments
Profession: Regional Consultant, *COPE (Coalition in Oregon for Parent Education)

Elsie Edge
9915 S.W. Killarney Lane
Tualatin, OR 97062
503 692-6157

Child's disability: Encephlocele; hydrocephalus; developmental delay
Group affiliations: Pilot Parents - Member, Steering Committee
Washington County Early Intervention Advisory Group - Chairperson
Oregon State Parents' Council for Early Intervention
Health care facility where child receives majority of care: Emanuel Hospital - Portland, OR
Skills and interests: Parent support and advocacy; networking at county and state level for continuum of education services; early intervention
Experience: Parent Representative for Oregon, Zero to Three Project; public speaking; participated in training for health providers/teachers; starting or maintaining support group

Pam Kourafas
2612 S.W. Tegart
Gresham, OR 97030
503 234-9991

Child's disability: Tuberous sclerosis
Group affiliation: Association for Severely Other Health Impaired (ASOHI) - Treasurer
Skills and interests: Increasing educational options; issues and services for children with chronic illness; parent/professional partnerships
Experience: Leading training for health providers/teachers; promoting legislation; starting or maintaining support groups; working with state health departments
Participation in ACCH Parent Network meetings (years): 1986

Frank Quan
12030 SE Woodward Place
Portland, OR 97266
503 251-9464

Child's disability: Quadriplegia with medical impairments
Group affiliation: Association for Severely Other Health Impaired (ASOHI) - Secretary
Health care facility where child receives majority of care: Oregon Health Sciences University - Portland, OR
Skills and interests: Parent advocacy at the state level
Experience: Promoting legislation; starting or maintaining support groups
Profession: Accounting, data processing

Niki Smith
840 Hood N.E.
Salem, OR 97303
503 581-5034

Child's disability: Down Syndrome
Group affiliations: *COPE (Coalition in Oregon for Parent Education) -Regional Consultant
ARC - Chair, Education Committee for Policy Review
Health care facility where child receives majority of care: Oregon Health Sciences University Hospital - Portland, OR
Skills and interests: Family support and advocacy; information "broker" on education issues; workshops for parents and professionals
Experience: Advocate, Oregon State Early Intervention Council; Member, State Training Center Review Board; public speaking; leading training for health providers/teachers; promoting legislation; starting or maintaining support groups
Profession: Regional consultant, *COPE

Becky Venice
138 North H Street
Cottage Grove, OR 97424
503 942-4269

Child's disability: Down Syndrome
Group affiliations: *COPE (Coalition in Oregon for Parent Education) - -Regional Consultant
ARC
National Down Syndrome Congress
Skills and interests: Development of independent living opportunities
Experience: Public speaking; leading training for health providers/teachers; promoting legislation; starting or maintaining support groups
Profession: Regional consultant, *COPE
Participation in ACCH Parent Network meetings (years): 1986

PENNSYLVANIA

Kathleen M. Cleaver
708 Summit Avenue
Philadelphia, PA 19128
215 482-1207

Child's disability: Cerebral palsy; mental retardation
Group affiliation: Parents Exchange
Health care facility where child receives majority of care: Children's Rehabilitation Hospital - Philadelphia, PA
Skills and interests: Develop and expand information and referral systems for families in Pennsylvania
Experience: Starting or maintaining support groups
Participation in ACCH Parent Network meetings (years): 1986

Laura Jenewicz
2583 Balwynne Park Road
Philadelphia, PA 19131
215 877-5111

Child's disability: Cerebral palsy
Group affiliation: Parents Exchange
Health care facility where child receives majority of care: Children's Rehabilitation Hospital - Philadelphia, PA
Skills and interests: Co-founder family information and referral system; expand information services for families in Pennsylvania
Experience: Starting or maintaining support groups; working with state health departments
Participation in ACCH Parent Network meetings (years): 1986

Carolyn F. Morris
7906 St. Martins Lane
Philadelphia PA 19118
215 247-9431

Child's disability: Cerebral palsy
Group affiliation: United Cerebral Palsy Association
Health care facilities where child receives majority of care: Kennedy Institute - Baltimore, MD; Children's Rehabilitation Hospital - Philadelphia, PA
Skills and interests: Parent support at local level
Experience: Promoting legislation

RHODE ISLAND

Joy Benson
10 C Sandy Point Farms
Portsmith, RI 02871
401 277-5497
401 847-7157

Child's disability: Spina bifida
Health care facilities where child receives majority of care: St. Joseph's Hospital - Providence, RI; Children's Hospital - Boston, MA
Skills and interests: Parent-to-parent support
Experience: Public speaking; leading training for health providers/teachers; starting or maintaining support groups;
Profession: Parent Consultant, Pediatric Oncology Service, Rhode Island Hospital
Participation in ACCH Parent Network meetings (years): 1983, 1984

Helena G. Richards
34 Gentian Drive
South Kingston, RI 02879
401 277-5497
401 783-9293

Child's disability: Leukemia (deceased)
Group affiliation: Candlelighters Childhood Cancer Foundation
Health care facility where child received majority of care: Rhode Island Hospital - Providence, RI
Skills and interests: Parent-to-parent support
Experience: Public speaking; leading training for health providers/teachers; starting or maintaining support groups; working with state health departments
Profession: Parent Consultant, Pediatric Oncology Service, Rhode Island Hospital
Participation in ACCH Parent Network meetings (years): 1985, 1986

SOUTH DAKOTA

Dawn Kellogg
1714 38th Street
Rapid City, SD 57702
605 341-1955

Child's Disability: Static encephalopathy; microcephaly; severe developmental delay
Group affiliations: Positive Parent Network
ARC
Health care facility where child receives majority of care: Rapid City Regional Hospital - Rapid City, SD
Skills and interests: Expanding parent-to-parent outreach throughout state; develop Parent Advisory Board at hospital
Experience: Parent Representative, State Health Advisory Board to Maternal and Child Health; Parent Representative, State Department of Special Education Interagency Council for developing and implementing guidelines for P.L. 99-457; public speaking; leading training for health providers/teachers; starting or maintaining support groups; working with state health departments
Profession: R.N.
Participation in ACCH Parent Network meetings (years): 1986

TENNESSEE

Nancy Dean
1305 Candlewick
Knoxville, TN 37922
615 690-6520

Child's disability: Blind
Health care facility where child receives majority of care: East Tennessee Children's Rehabilitation Center - Knoxville, TN
Skills and interests: Parent-to-parent support; developed Mother's Day Out Program; developing sibling groups
Experience: Leading training for health providers/teachers; starting or maintaining support groups
Participation in ACCH Parent Network meetings (years): 1986

Mary Goldsack
415 Wrather
Murfeesboro, TN 37130
615 893-1449

Child's disability: Cancer (rhabdomyosarcoma)
Group affiliation: Parents of Special Children
Health care facility where child receives majority of care: Vanderbilt University Hospital - Nashville, TN
Skills and interests: Parent-to-parent support program facilitator; hospital visitation policies
Experience: Public speaking; starting or maintaining support groups
Profession: R.N.; Prenatal class instructor
Participation in ACCH Parent Network meetings (years): 1983, 1985

Kathleen Rutherford
301 Hillcrest
Clinton, TN 37716
615 690-8961
615 457-2793

Child's disability: Cerebral palsy; seizures
Health care facility where child receives majority of care: East Tennessee Children's Rehabilitation Center - Knoxville, TN
Skills and interests: Parent-to-parent support; sibling support; parent/professional collaboration; early intervention
Experience: Vice President, POSTOP (Parents Offering Support to Other Parents); Parent Volunteer, Mother's Day Out Program; Parent Counselor, Crippled Children's Services Clinic; Knox County Chairperson, Cerebral Palsy of East Tennessee; Member, East Tennessee Coalition for Young Children; starting or maintaining support groups; working with state health departments
Participation in ACCH Parent Network meetings (years): 1986

TEXAS

Kathy Angel
5320 Montrose Boulevard
Houston, TX 77005
713 528-4528

Child's disability: Juvenile rheumatoid arthritis
Group affiliation: American Juvenile Arthritis Association - President
Skills and interests: Developing training programs for parent advocacy; organizing national conferences on rheumatoid diseases for families and health professionals
Experience: Member, Advisory Panel, Regional Pediatric Rheumatology Center, Texas Children's Hospital; public speaking; promoting legislation; starting or maintaining a parent support group
Participation in ACCH Parent Network meetings (years): 1984

Ellen Day
6727 Beauford Drive
Austin, TX 78750
512 478-6132
512 346-7449

Child's disability: Spina Bifida
Group affiliations: Spina Bifida Association of Texas - Executive Director
Coalition of Texans with Disabilities
Health care facility where child receives majority of care:
Brackenridge Hospital - Austin, TX
Skills and interests: Educational advocacy
Experience: Advisory Board, Brackenridge Hospital; Clinic Volunteer, Brackenridge Hospital; public speaking; leading training for health providers/teachers; promoting legislation; starting or maintaining support groups; working with state health departments

Pat Downey
807 Stetters
Arlington, TX 76017
817 467-7565

Child's disability: I-cell disease (deceased)
Health care facility where child received majority of care: Lutheran General - Parkridge, IL
Skills and interests: Freelance writer
Experience: Author of two booklets published by ACCH: Let's Play with Our Children and New Directions for Exceptional Parenting; public speaking; leading training for health providers/teachers; promoting legislation; starting or maintaining support groups
Profession: Purchasing clerk

Elizabeth Ferguson
5331 Spring Meadow
Dallas, TX 75229
214 368-3754

Child's disability: Juvenile nephronophthisis
Group affiliations: Renal Family Support Team - Chairman
Children's Kidney Fun Kamp
Health care facility where child receives majority of care: Children's Medical Center - Dallas, TX
Skills and interests: Coordinating camp for children with kidney problems; parent-to-parent support
Experience: Parent Volunteer, Children's Medical Center
Profession: Choreographer and performing artist
Participation in ACCH Parent Network meetings (years): 1985, 1986

Vicki Franzen
4921 Wildbriar
Garland, TX 75043
214 279-0057

Child's disability: Leukemia (ALL)
Group affiliations: Children's Cancer Fund - Vice President of Fund Raising
Candlelighters Childhood Cancer Foundation
Health care facility where child receives majority of care: Children's Medical Center - Dallas, TX
Skills and interests: Fund raising
Experience: Public speaking
Participation in ACCH Parent Network meetings (years): 1985

Barbara Ginsburg
4034 Leeshire Drive
Houston, TX 77025
713 667-7485

Child's disability: First Branchial Arch Syndrome; mental retardation
Group affiliation: Confident Parenting Programs - Director
Skills and interests: Parent-to-parent support programs; workshops for families and educators about child development and disabilities; outreach to families
Experience: Conducting parent education programs; working with local Mental Health Mental Retardation Authority; public speaking; leading training for health providers/teachers
Profession: Director, Confident Parenting Programs
Participation in ACCH Parent Network meetings (years): 1986

Ann and Jerry Hendon
503 Hillhurst
Baytown, TX 77521
713 656-7336
713 427-5977

Child's disability: Cystic fibrosis (deceased)
Group affiliation: Cystic Fibrosis Parents Support Group
Health care facility where child received majority of care: Texas Children's Hospital - Houston, TX
Skills and interests: Parent-to-parent support; parent/professional collaboration; educational meetings for parents
Experience: Starting or maintaining support groups

Susan Kalen
3424 Marguette
Dallas, TX 75205
214 739-3568

Child's disability: Asthma
Health care facility where child receives majority of care: Children's Medical Center - Dallas, TX
Experience: Board Member, Women's Auxiliary, Children's Medical Center
Participation in ACCH Parent Network meetings (years): 1985

Jan Navarre
2126 Kowis
Houston, TX 77093
713 987-3291

Child's disability: Juvenile rheumatoid arthritis
Group affiliation: American Juvenile Arthritis Association
Health care facility where child receives majority of care: Texas Children's Hospital - Houston, TX
Skills and interests: Parent support and education; sports programs for children with disabilities
Experience: Leading training for health providers/teachers; starting or maintaining support groups
Profession: Accountant
Participation in ACCH Parent Network meetings (years): 1984

Brenda Rapp
1906 Clemson
Richardson, TX 75081
212 234-8727

Child's disability: Cystic fibrosis
Group affiliation: Cystic Fibrosis Foundation
Health care facility where child receives majority of care: Children's Medical Center - Dallas, TX
Skills and interests: Parent and family advocacy; continuing education on cystic fibrosis for patients and families; insurance concerns at state level
Experience: Chairperson, Patient Services Committee; Advisor to Public Policy Committee; Board Member, Cystic Fibrosis Foundation; Committee Member, Cystic Fibrosis Information Time; public speaking; leading training for health providers/teachers; promoting legislation; starting or maintaining support groups; working with state health departments
Participation in ACCH Parent Network meetings (years): 1985, 1986

UTAH

Pat Shifflett
6393 Silver Bell
Murray, UT 84107
801 261-3918

Child's disability: Cerebral palsy
Group affiliations: Developmental Disabilities Preschool and Early Intervention Program
Legal Coalition of Handicapped Persons
Health care facility where child receives majority of care:
Handicapped Children's Services - Salt Lake City, UT
Skills and interests: Networking and parent support
Experience: Member, State Advisory Board to make policy for the 0-3 population;public speaking; promoting legislation; starting or maintaining support groups; working with state health departments
Profession: Nursing student (BSN)

VERMONT

Debra R. Asselin
Welch Road
Topsham, VT 05076
802 439-5282

Child's disability: Premature birth, bronchopulmonary dysplasia
Group affiliation: Parents of Premies
Health care facility where child receives majority of care:
Massachusetts General Hospital - Boston, MA
Skills and interests: Parent-to-parent support groups; training and support for families
Experience: Public speaking; leading training for health providers/teachers; starting or maintaining support groups; working with state health departments

VIRGINIA

Cyndi Cline
10913 Belvoir Road
Chester, VA 23831
804 748-4881

Child's disability: Bronchopulmonary dysplasia; ventilator dependent
Group affiliations: SKIP of Virginia - Director
American Lung Association of Southside Virginia - Board member
Health care facility where child receives majority of care: Medical College of Virginia - Richmond, VA
Skills and interests: Parent support; increasing public awareness of needs of technology dependent children; promoting legislation for medicaid home care waiver system
Experience: Public speaking; promoting legislation; starting or maintaining support groups; working with state health departments
Profession: Parent Advisor, Parent-to-Parent; dental assistant
Participation in ACCH Parent Network meetings (years): 1986

Sue Ferguson
505 East Columbia Street
Falls Church, VA 22046
703 237-9089

Child's disability: Cerebral palsy; seizure disorder
Health care facility where child receives majority of care: Georgetown University Hospital - Washington, DC
Skills and interests: Developing case management services for families; promoting legislation
Experience: Degrees and experience in special education

Jane Purdy
4615 Gramlee Circle
Fairfax, VA 22032
703 978-4111

Child's disability: Cerebral palsy; learning disability
Group affiliations: Northern Virginia ACLD
ARC
Committee for Exceptional Children
Health care facility where child receives majority of care: Children's Hospital National Medical Center - Washington, DC
Skills and interests: Public speaking and writing; parent-to-parent support; consulting to families of children with special needs
Experience: Public speaking; leading training for health providers/teachers; starting or maintaining support groups; working with state health departments
Profession: R.N.; Special Needs Family Consultant, U.S. Coast Guard
Participation in ACCH Parent Network meetings (years): 1985

Greg and Lori Weigle
451 Orchard Street
Vienna, VA 22180
703 281-1211

Children's disabilities: Down Syndrome
Down Syndrome
Seizure disorder; failure to thrive
Group affiliations: Alliance of Genetic Support Groups
Parents of Down Syndrome Children
National Down Syndrome Congress
Health care facilities where children receive majority of care: Children's Hospital National Medical Center - Washington, DC; Fairfax Hospital - Fairfax, VA
Skills and interests: Advocacy at the state and national level; assist with foster care, adoptions and parent outreach; professional education
Experience: Public speaking; leading training for health providers/teachers; promoting legislation; starting or maintaining support groups; working with state health departments

Beth Wroblewski
6160 Martins Landing Court
Burke, VA 22015
703 250-0930

Child's disability: Malabsorption; intractable diarrhea; allergic enteropathy
Group affiliation: Parents of Chronically Ill Children - Co-founder
Health care facility where child receives majority of care: Georgetown University Hospital - Washington, DC
Skills and interests: Parent-to-parent support and networking
Experience: Starting or maintaining support groups; working with state health departments
Participation in ACCH Parent Network meetings (years): 1986

WASHINGTON

Barbara Bilyeu
2603 North Union Avenue
Tacoma, WA 98407
206 272-7804
206 759-7933

Child's disability: Sturge-Weber Syndrome
Group affiliation: *PAVE (Parents Advocating Vocational Education) - Parent Trainer
Parent to Parent Training Project
Skills and interests: Parent training in PL 94-142; least restrictive environment, normalization, transition
Experience: Past President, Parents Advisory Council, Federal Way Local Education Agency; speaker on educational rights and responsibilities for parents of children with special needs; leading training for health providers/teachers; promoting legislation; starting or maintaining support groups;
Profession: Parent trainer, *PAVE
Participation in ACCH Parent Network meetings (years): 1986

Jo Butts
1010 South I Street
Tacoma, WA 98405
206 272-7804
206 893-2395

Child's disability: Cerebral palsy; learning disability
Group affiliations: *PAVE (Parents Advocating Vocational Education) - Assistant Director
TAPP (Technical Assistance for Parents Program) - Technical Assistance Coordinator
Health care facility where child receives majority of care: Good Samaritan Children's Therapy Unit - Puyallup, WA
Skills and interests: Support for parents; leading training in PL 94-142
Experience: Public speaking; leading training for health providers/teachers; starting or maintaining support groups
Profession: Assistant Director, *PAVE

WEST VIRGINIA

Joyce P. Altizer
4613 Sixth Avenue
Vienna, WV 26105
304 295-5435

Child's disability: Multiple congenital disabilities
Group affiliation: We've Been There
Skills and interests: Parent-to-parent support; workshops for health care professionals on need to improve services; early childhood/special education
Experience: Serving on State Interagency Committee for Preschoolers with Handicaps; public speaking; leading training for health providers/teachers; promoting legislation; starting or maintaining support groups; working with state health departments
Participation in ACCH Parent Network meetings (years): 1986

WISCONSIN

Valerie Schreiner
203 Brookfield Drive
Stratford, WI 54484
715-687-4551

Child's disability: Short bowel syndrome
Group affiliation: Parent Support Group - Founder
Health care facility where child receives majority of care: Marshfield Clinic - Marshfield, WI
Skills and interests: Parent-to-parent support; working with families after hospital discharge
Experience: Starting or maintaining parent support group
Profession: R.N.

CANADA

ALBERTA

Phyllis Kane
6803 54th Avenue, N.W.
Calgary, AB T3B 3N4
403 247-3055

Children's disabilities: Asthma; allergy
Asthma; allergy
Asthma; allergy; spondylolisthesis
Group affiliations: Children's Hospital Community Advisory Committee-Chairperson
Allergy/Asthma Association of Calgary - Founder
Health care facility where children receive majority of care: Alberta Children's Hospital - Calgary, Alberta
Skills and interests: Respite care for medically fragile; early intervention resources for hamdicapped children; care by parent units in hospitals
Experience: Chairperson, Alberta Children's Hospital Community Advisory Committee; public speaking; conducting seminars for health providers/teachers; promoting legislation; starting and maintaining support groups; working with provincial health departments
Participation in ACCH Parent Network meetings (years): 1986

Nancy Watson
Alberta Children's Hospital
Parent Services
1820 Richmond Road, S.W.
Calgary, AB T2T 5C7
403 229-7281
403 243-2275

Child's disability: Cerebral palsy
Group affiliation: Cerebral Palsy Association of Calgary
Health care facility where child receives majority of care: Alberta Children's Hospital - Calgary, Alberta
Skills and interests: Parent-to-parent support; parent/professional collaboration; improve continuity of care for families
Experience: Representative, Community Advisory Committee, Alberta Children's Hospital
Profession: Parent services in outpatient clinics, Alberta Children's Hospital
Participation in ACCH Parent Network meetings (years): 1986

BRITISH COLUMBIA

Valerie L. Brotherton
P.O. Box 2195
Sechelt BC V0N 3A0
604 885-7033
604 885-2910

Child's disability: Kasabach-Merritt Syndrome; cavernous hemangioma (deceased)
Group affiliation: Network for Kasabach-Merritt Syndrome - Founder
Health care facility where child received majority of care: Children's Hospital - Vancouver, British Columbia
Skills and interests: Parent-to-parent support; establishing parent network
Experience: Public speaking; starting or maintaining support groups

Sandra Williams
1790 Kilpatrick Avenue
Courtenay, BC V9N 2Y6
604 338-8879

Child's disability: Congenital heart disease
Group affiliation: Y.A.N.A. (You Are Not Alone) - President
Comox Valley Charitable Bingo Association - Board Member
Health care facility where child receives majority of care: Children's Hospital - Vancouver, British Columbia
Skills and interests: Providing funding for families leaving Comox Valley for medical care; psychosocial effects of hospitalization on families; networking with local hospitals; fundraising
Experience: Public speaking; leading training for health providers/teachers; starting or maintaining support groups; working with provincial health departments
Profession: Sales clerk

NOVA SCOTIA

Scott Dickson
300 Micmac Boulevard #318
Dartmouth, NS B3A 4L6
902 466-3332

Child's disability: Leukemia
Group affiliation: Maritime Candlelighters Childhood Cancer Foundation - President
Health care facility where child receives majority of care: Izaak Walton Killam Hospital for Children - Halifax, Nova Scotia
Skills and interests: Parent support; fundraising, planning family activities and monthly meetings
Experience: Public speaking; starting or maintaining support groups
Profession: Graphic designer

Carol Young
1191 Dalhousie Street
Halifax NS B3H 3W5
902 422-9452

Child's disability: Renal transplant; blind
Group affiliation: Canadian National Institute for the Blind (CNIB)
Ronald McDonald House - Board Member
Health care facility where child receives majority of care: Izaak Walton Killam Hospital for Children - Halifax, Nova Scotia
Skills and interests: Improve hospital services to meet the needs of children and families; parent support
Experience: Member, Board of Governors, Izaak Walton Killam Hospital for Children; Board Member and Volunteer, Ronald McDonald House; public speaking; starting or maintaining support groups
Participation in ACCH Parent Network meetings (years): 1986

ONTARIO

Kathleen Jordan
5 Holgate Court
Kanata, ONT K2K 1B4
613 592-2678

Child's disability: Cerebral palsy; visual impairment; seizure disorder
Group affiliations: Ottawa Crippled Children's Parent Group
Special Educational Advisory Committee, Carlton Roman Catholic School Board
Easter Seals Society - Parent Delegate
Health care facilities where child receives majority of care: Children's Hospital of Eastern Ontario (CHEO) - Ottawa, Ontario; Ottawa Children's Treatment Center - Ottawa, Ontario
Skills and interests: Outreach to families with special needs children; networking with parents across the province; advocate for improved educational programs and services for exceptional children
Experience: Board Member, Views for the Visually Impaired; Member, Participating Families, Ontario Federation for the Cerebral Palsied; Consumer and Child Advocate, Provincial Ministry of Health Advisory Committee to the Minister on Assistive Devices; Member, Advisory Committee, Canadian Diabetic Association; public speaking; leading training for health providers/teachers; starting or maintaining support groups; working with provincial health departments
Profession: Member, Federal Human Rights Tribunal Panel; educator

Elaine Orrbine
155 Owl Drive
Ottawa, ONT K1V 9J5
613 737-2572
613 526-4242

Child's disability: Nephrotic Syndrome
Group affiliation: Kidney Foundation of Canada
Health care facility where child receives majority of care: Children's Hospital of Eastern Ontario - Ottawa, Ontario
Skills and interests: Author of handbook for parents of children with nephrotic syndrome - Childhood Nephrotic Syndrome, You and Your Child; working on handbook for parents on end-stage renal disease
Experience: Public speaking; starting or maintaining support groups
Profession: Coordinator, Canadian Pediatric Kidney Disease Reference Center

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Association for the Care of Children's Health

Humanizing Health Care for Children and Their Families

3615 Wisconsin Avenue, N.W.
Washington, D.C. 20016
(202) 244-1801

PARENT RESOURCE DIRECTORY INFORMATION FORM FOR 2ND EDITION

Please complete this form with any changes in your entry in this directory or pass on to a parent for the next edition of the directory to be published in the summer of 1987.

PLEASE PRINT OR TYPE.

1. Name_____

   Address_____

   City_____ State_____ Zip_____

   Phone (day) (___)_____ (night) (___)_____

2. Child's disability _____

   (Please indicate if more than one child has a disability and the disability for each child.)

   _____

   _____

3. Name of health care facility where child receives majority of care_____

   Address_____
   City State Zip

   Any affiliation with this health facility beyond your role as a parent? Yes_____ No_____

   If yes, please specify your role_____

   _____

ACCH was formerly the Association for the Care of Children in Hospitals

4. Are you affiliated with any groups or organizations (i.e., disease specific organizations, parent support group)? List as many as you want, including your title and position.

_____

_____

_____

5. What are your skills, interests or current activities as related to improving child health care or education services?

_____

_____

_____

6. Do you have experience in any of the following areas?

Public speaking? Yes_____ No_____

Conducting training sessions for health care providers or teachers?
Yes_____ No_____

Promoting legislation? Yes_____ No_____

Starting or maintaining a parent/family support group?
Yes_____ No_____

7. What is your profession? _____

Are you currently employed? Yes _____ No_____

If yes, in what capacity and where? _____

_____

8. Do you have any affiliation with a federally funded Parent Training and Information Center?

Yes_____ No_____

If yes, which one and where?_____

_____

9. Please describe your involvement with your state's health department.

____ Have you had any involvement with state health agencies? In what way? _____

_____

____ Have you worked closely with your state health department?
In what way? _____

_____

____ Does your child receive health care services from a state health department?

Please describe._____

_____

10. Have any of your children ever been involved with Head Start? Yes_____ No_____

If yes, what year? _____ Where?_____

11. Have you ever attended any ACCH Parent Network meetings?

_____ 1983 - Chicago

_____ 1984 - Houston

_____ 1985 - Boston

_____ 1986 - San Francisco

_____ 1987 - Halifax

12. Below is a list of community services and resources that can be supportive of families caring for children with special needs. Please indicate which services have been of assistance to you.

_____ Babysitting services

_____ Camps

_____ Day care program

_____ Early intervention program

_____ Equipment loan or exchange program

_____ Family resource library

_____ Financial assistance for supportive services (not for direct health care)

_____ Foster grandparent program or similar volunteer program

_____ Home tutoring program

_____ Hospice

_____ In-home nursing care

_____ Lekotek or toy lending library

_____ Parent information center

_____ Parent-to-parent support

_____ Respite care

_____ Sibling support program

_____ Transportation assistance

_____ Other _____

_____

Please return to ACCH by June 15, 1987.

Association for the Care of Children's Health

Humanizing Health Care for Children and Their Families

3615 Wisconsin Avenue, N.W.
Washington, D.C. 20016
(202) 244-1801

PARENT RESOURCE DIRECTORY EVALUATION FORM

1. In what ways have you used, or might you use, this directory?

2. What other kinds of information would you like to see included in this directory?

3. What suggestions do you have for improving the usefulness or format of this directory?

4. Do you have suggestions for people and/or organizations to receive this directory?

5. Other comments:

Please return this form to ACCH.

ACCH was formerly the Association for the Care of Children in Hospitals

The Association for the Care of Children's Health (ACCH) is an organization of health care professionals and parents which seeks to foster and promote the psychosocial well-being of children and families in health care settings through education, multidisciplinary interaction, and research. Founded in 1965, ACCH has over 3900 members and 50 regional affiliates which offer local and regional educational programs.

This publication has been developed as part of a project funded by the Division of Maternal and Child Health, HHS. The project's overall purpose is to promot[illegible]rent/professional collaboration and a family-centered approach to health care for infants, children, and adolescents with a chronic illness or disabling condition.